

## **We need to talk about Palliative Care**

**Rebecca Kellett**

Rebecca Kellett, Speech and Language Therapist with 20 years experience working with people with acquired neurological conditions in the community. This is a personal response and does not necessarily reflect the views of my professional body.

A. Access. This can be ensured if there is a Palliative Care Consultant with a team of doctors and nurses who can accept direct referrals from health professionals for people with any type of terminal illness.

I'm not sure if palliative care workers have any expectation of talking to the wider multi-disciplinary team. I think it would be great to have a named care worker who kept in touch with all the other team members (helped by electronic records). We tried this where I used to work, and the Macmillan nurse took on this role. Patients and families found it helpful to have a single point of contact, and it prevented piecemeal interventions. The named care worker does need to be very well informed about other services and when and how to signpost.

B. As a community therapist, some of my worst experiences in end of life care have arisen because families looking after a dying patient at home have not been told by the GP that the person is nearing the end of life. These are patients who would not have been identified as needing palliative care, but a small amount of input from somebody who was knowledgeable about end of life issues would have helped enormously. GPs must not be afraid of saying when they do not expect a person to live. Could there be a quick response brief intervention, or would training for our own team cover this?

Using the word "palliative" does suggest to people that the person may be dying imminently, even though palliative services may be accessed long before the end of life. I'm not sure whether there's a solution to this. I've often found it is the family rather than the terminally ill person who react badly to the words being used. The person themselves is sometimes relieved that "palliative" has been acknowledged.

Anticipatory care plans were often drawn up with the Palliative Care Consultant in my previous job. In my new area that service does not seem to be available and I think people are much more frightened if they haven't had that opportunity. Care plans (like birth plans) don't always get followed, but it helps survivors to know that wishes were understood and acknowledged. When the person who is dying is losing cognitive function, it is very important to find out wishes early on, though situations sometimes change so much the plans cannot be adhered to. A good understanding of capacity issues is important for all those involved.

Good palliative care is sensitive to the person and their needs, and everybody is different. It is imperative that we don't end up with a formulaic approach to this. It is very difficult to anticipate when someone will want information, but

we do need to make sure they know early on how they can access it, and it must be available in different formats.

I've never had any training on this even though my role has brought me in to contact with terminally ill people near the end of their lives. I've often raised this with managers – some teams get more training and support than others. We want to be doing the best for our patients and there are times when we are the only people involved. I think training should be a given, and also opportunities to reflect with others and learn from our experiences.

C. Record keeping. Electronic records will make this work more smoothly. As for outcomes, we've looked at measures for quality of end of life care and they all make us feel uncomfortable. It feels intrusive asking people to rate interventions at this critical time, and the way people respond depends so much on the situation that day. My favourite way to look at outcomes is by collecting patient stories, perhaps with the family some time after the person has died. I think it is important that we value this as good quality evidence and don't just give weight to numeric data. I don't know about the evidence from other countries.

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